

# Psychological well-being in people with multiple sclerosis in an Iranian population

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**Background:** To date, few results on well-being in individuals with neurological disease have been published, while several studies in other groups have indicated that well-being may not be the only absence of psychological distress, but also positive psychological function. The aim of the present study was to compare the psychological well-being (PWB) between the people with Multiple sclerosis (MS) and normal individuals and identify correlated demographic factors to PWB in people with MS disorder. **Materials and Methods:** A case-control study was performed in July 2012 on 55 people with MS who were referred to MS clinic (located at the Kashani Hospital), Isfahan Neurosciences Research Centre and 83 normal individuals with matched mean of age, level of education, and gender. The participants filled up the 18-item Ryff's PWB and demographic profile. The data were analyzed by SPSS software based on the independent *t*-test, and ANOVA. **Results:** There is significant different in all PWB dimensions between people with MS and normal groups. There were no significant differences in PWB in people with MS in relation to gender and marital status, but individuals with higher level of education scored higher in total PWB, positive relationship with others and purpose in life. **Conclusion:** People with MS are at risk of lower level of PWB. Interventional programs for improving PWB are strongly recommended.

**Key words:** Multiple Sclerosis, psychological well-being, quality of life

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## INTRODUCTION

Multiple sclerosis (MS) is an immune-mediated, neurodegenerative disease that affects an estimated 2.5 million adults worldwide.<sup>[1]</sup> In Isfahan/Iran, an increase in prevalence and incidence figures (73.3; 9.1: 2004-2005 vs. 43.8; 3.64: 2003-2010/1,00,000) was reported.<sup>[2,3]</sup> MS typically has its onset in early adulthood, and affects more women than men. Although rarely fatal, MS produces a range of unpleasant and disabling symptoms. The course of MS is idiosyncratic and unpredictable. This disease manifests in a wide range of symptoms including muscle weakness, extreme fatigue, imbalance, visual, speech disturbances, and cognitive impairment. Such symptoms often lead to poor health-related quality of life (HRQOL),<sup>[3-5]</sup> neurologic disability, and high health care costs.<sup>[7]</sup>

MS poses multiple challenges for both physical and psychological well-being (PWB) people with MS experience unpleasant and unpredictable symptoms, difficult treatment regimes, and drug side effects, and increasing levels of physical disability. They also face psychosocial consequences including disruptions to life goals, employment, income, relationships, leisure activities, and daily living activities. Psychological difficulties are extremely common in MS compared to both healthy populations and other chronic diseases. The empirical literature attests to elevated rates of depression and distress,<sup>[8]</sup> increased anxiety,<sup>[9]</sup> low subjective well-being, quality of life (QOL),<sup>[8,10]</sup> social role and relationship difficulties.<sup>[11]</sup> Nonetheless, a substantial proportion of people with MS manage to adapt well to living with the illness.<sup>[12]</sup> Illness factors such as the extent of neurological disability, symptom severity, remission status, and length of illness can influence

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levels of psychological adjustment in MS.<sup>[13]</sup> However, these factors are inconsistently associated with adjustment, and are often only modest predictors.<sup>[14]</sup> Research demonstrates that psychological factors are often better predictors of individual differences in adjustment than illness factors.<sup>[15]</sup> Psychological factors, unlike illness factors, are potentially modifiable through psychological interventions. Studies on emotional distress and HRQOL broadened the traditional biomedical focus in MS research, but little attention was paid to total well-being indicators. Although research on these topics has broadened the traditional biomedical focus to include subjective evaluations of living conditions, the limitations of such approach are increasingly evident. First, in MS literature QOL is substantially related to health issues, while other relevant life domains are neglected.<sup>[16]</sup> Second, research and intervention primarily target physical and emotional symptoms, namely the negative aspects of illness. Such focus implicitly equates health with the absence or reduction of disease/infirmity, and not with a state of complete physical, mental, and social well-being, as defined by the WHO. In this respect, psychologists recently called for a shift in attention from human shortcomings and deficits to personal resources and potentials, showing through empirical studies that well-being is not the opposite of ill-being; rather, it comprises unique dimensions.<sup>[17,18]</sup> Well-being studies refer to two conceptual approaches. The hedonic one focuses on emotions and operationalizes well-being as life satisfaction and prevalence of positive over negative affect (hedonic balance).<sup>[19]</sup> The eudaimonic approach focuses on meaning-making and goal pursuit.<sup>[20,21]</sup> One of the eudaimonic constructs is PWB, purport by Ryff<sup>[22]</sup> that well-being is a multi-dimensional construct made up of life attitudes necessary for positive functioning. This conception of QOL has been termed by Ryff as "PWB" and has received extensive empirical support.<sup>[22-25]</sup> Ryff<sup>[22]</sup> suggests a model representative of six dimensions of well-being:

1. Self-acceptance (SA); the ability to feel good about oneself while being aware of one's limitations,
2. Environmental mastery (EM); the attempt to shape one's environment to meet personal needs and wishes,
3. Positive relations with others (PR); having affirming relationships with others,
4. Personal growth (PG); making the most of one's capability and skills,
5. Purpose in life (PL); ability to find meaning in one's struggles or hardships, and
6. Autonomy (A); seeking a sense of personal authority and independence.

The experience of having MS has the potential to impact seriously each one of these aspects of well-being, but little research has examined these constructs in MS population. Research has shown that conditions such as chronic disease

are not necessarily perceived as stressful threats.<sup>[20]</sup> They can also be interpreted as challenges and opportunities for growth, thus not hampering well-being, especially its eudaimonic components such as meaning-making, interpersonal relations, and engagement in daily activities.<sup>[23]</sup> Accordingly, in the few studies targeting hedonic well-being in MS research, people with MS were more dissatisfied with their lives than healthy individuals.<sup>[24,25]</sup> As for eudaimonic well-being, only a few studies were carried out: It showed that people with MS and healthy controls reported similar levels of PG.<sup>[26]</sup> Well-being (both hedonic and eudaimonic aspects) decreased with a higher disability. Psychological distress was moderately related to eudaimonic well-being.<sup>[27]</sup> Hart *et al.* found that treating depression was significantly associated with improvements in 4 of the 6 scales of PWB included EM, positive relations, PL, and self acceptance.<sup>[28]</sup> Because there is no published research on PWB in the Iranian population, we decided to examine PWB in people with MS in comparing to normal individuals. The aims of the present study were to compare PWB in people with MS with normal people in Isfahan, Iran, and to determine whether there are relationships between demographic variables and PWB in MS population.

## MATERIALS AND METHODS

Fifty-five male and female people with MS and 83 people with no neurological diseases aged 18-60 years were included in this case-control study, which was conducted in July 2012. The people with MS randomly were selected from MS clinic (Kashani Hospital, Isfahan Neurosciences Research Centre). Sample selection was based on their agreement to participate in this study. Criteria for the participants with MS were:

1. Diagnosed by a neurologist based on systemic examination and laboratory findings such as magnetic resonance imaging and
2. No other neurological and psychiatric disorders. The normal sample also was selected through multistage sampling from 15 municipal zones in Isfahan.

18-item version of the PWB scales developed by Ryff<sup>[22]</sup> was used to assess PWB. Ryff's measure defines well-being as a composition of six different psychological constructs include A: Independence and self-determination, SA: Positive attitude towards oneself and one's past life, EM: the ability to manage one's life, PR: Having satisfying high quality relationships, PG: Being open to new experiences, PL: Believing that one's life is meaningful. The participants were asked to grade their agreement to the sentences in seven categories, from strong disagreement to a strong agreement. The responses were coded from 0 to 6 and summed across the three items of each dimension. Some items were reversed, and all items randomly distributed in

an attempt to keep participants from seeing a pattern. The instrument, in this study showed varied internal consistency reliability for the six subscales:

1. A (Cronbach's  $\alpha = 0.34$ ),
2. EM (Cronbach's  $\alpha = 0.56$ ),
3. SA (Cronbach's  $\alpha = 0.78$ ),
4. PL (Cronbach's  $\alpha = 0.42$ ),
5. PG (Cronbach's  $\alpha = 0.58$ ), and
6. PR (Cronbach's  $\alpha = 0.34$ ).

A total psychological well-being (TPWB) score was calculated by adding all six constructs (Cronbach's  $\alpha = .7$ ). The same results seen in reported in other studies.<sup>[29]</sup> The data were analyzed by SPSS software (version 19.0; SPSS Inc., Chicago, IL, USA). *T*-test was performed to examine the differences in PWB scales in two normal and MS samples. ANOVAs were conducted to examine differences in PWB scales in MS group with regard to gender, married status, and level of education.

This study was approved by the local Ethics Committee and all patients in this study, and all subjects gave their written consent.

## RESULTS

Demographic characteristics of two samples are presented in Table 1. As shown in Table 2, people with MS reported lower level PWB in all subscales than the normal group.

According to the Table 3 there is no significant difference in TPWB in people with MS regard to gender and married status, but individuals with a higher level of education reported higher TPWB. For exploring relationship between the level of education and PWB in details, ANOVAs were conducted for subscales of PWB. The results showed that patients with higher level of education reported a higher level of PR and PL.

## DISCUSSION AND CONCLUSION

Our results indicate a reduction in all aspects of PWB of people with MS in comparison to the normal population and only the level of education has significantly positive relationship to PWB in MS group. Reduction in PWB compared with the general population had been seen in other studies.<sup>[10,24-27]</sup> The burden of living with MS affects patient's physical and mental health. Reduction in PWB could be attributed directly and indirectly to the symptoms and outcomes of MS disease. People with MS are faced with uncertainty about the future, unpleasant and unpredictable symptoms, difficult treatment regimes, and drug side effects. MS can have profound consequences, including disruption of life goals, employment, income, relationships,

**Table 1: Demographic characteristics of two samples**

Variable	MS n (%)	Normal n (%)
Gender		
Male	11 (20)	29 (33)
Female	44 (80)	59 (67)
Married status		
Single	40 (73)	58 (65)
Married	15 (27)	30 (35)
Level of education		
Lower than diploma	10 (18)	17 (19)
Diploma	32 (58)	51 (58)
Upper than diploma	13 (24)	20 (23)

MS = Multiple sclerosis

**Table 2: A comparison of the mean scores for the psychological well-being scales in patients with MS**

Variables	Mean	SD	P
A (MS/normal)	6/12.7	1.4/2.8	0.00
SA (MS/normal)	10/12	3/3	0.00
EM (MS/normal)	4.2/13.7	1.5/2.5	0.00
PR (MS/normal)	5.2/13.4	3/2	0.00
PG (MS/normal)	6.4/13.5	1.6/3.1	0.00
PL (MS/normal)	5.1/12.3	1.5/3	0.00
TPWB (MS/Normal)	37.4/77.8	6.7/11	0.00

A=Autonomy; SA = Self-acceptance; EM = Environmental mastery; PR = Positive relations; PG = Personal growth; PL = Purpose in life; TPWB = Total psychological well-being; MS = Multiple sclerosis; SD = Standard deviation

**Table 3: Total psychological well-being regard to gender, married status and level of education in MS sample**

Variables	n	Mean	SD	P
Gender				
Male	11	36.4	8.3	0.5
Female	44	37.7	6.2	
Married status				
Married	40	37.6	6.4	0.6
Single	15	36.3	8.8	
Level of education				
Lower than diploma	10	33.3	6.5	0.02
Diploma degree	32	37	6.4	
Upper than diploma	13	41	5.8	

MS = Multiple sclerosis; SD = Standard deviation

social, leisure activities, and activities of daily living. This may be particularly significant because, for the majority of people with MS, the disease begins in young adulthood, a period that is often important for career development and starting families. Therefore, it is not surprising that many patients experience many difficulties in PWB.<sup>[30]</sup> Individuals with low positive well-being were 7.16 times more likely to be depressed 10-years later.<sup>[31]</sup>

Research demonstrated elevated levels of depression<sup>[5]</sup> in people with MS. Thus interventional programs for promoting PWB could be a result to decrease depression. Historically the management of MS has been predominantly about limiting disability by the symptomatic management

of acute relapses and attempting to influence the long-term course. Even though this type of management is important, we suggest this is accompanied by an equal effort at improving participation PWB. Because the previous studies showed that both physical and psychological aspects are important and interact with each other.<sup>[32]</sup>

It is necessary to continue the research on PWB in people with MS to evaluate the impact of factors such as the type of pharmacological treatment and rehabilitation.

Regarding the correlation between PWB and level of education, we believe that firstly it is assumed that MS symptoms are to be diagnosed sooner in people with higher education, thus treatment affairs sooner be started and consequence impairment in PWB would be minimized. In the other hand, there is more purpose for people with higher education especially who enter to universities in life, and they have a broader range of relationship options. The limitations of this study were the lack of a control group. The limitations of this study were the lack of a control group. Furthermore, patients who participated in this research in terms of disability were mild to moderate.

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### Conflicts of interest

There are no conflicts of interest.

### AUTHORS' CONTRIBUTION

SRD contributed in the conception of the work, conducting the study, revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work as first author. FH contributed in the conception of the work, conducting the study, Data analysis and agreed for all aspects of the work. FA contributed in the conception of the work, conducting the study, revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work. VSh contributed in the conception of the work, conducting the study, revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work. All authors have read and approved the content of the manuscript and are accountable for all aspects of the work.

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